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Engaging with the national health information committees

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Summary

In the federally-dispersed health system that exists in Australia, strong governance arrangements are needed to ensure that health information, collected under different health administrations, are consistent and therefore accurate and useful for policy, planning and program management.

The governance mechanisms for health information are established under the Australian Health Ministers Conference (AHMC), with particular committees vested with delegated authority to endorse national standards and definitions.

This document provides guidance on engaging with the national processes responsible for health information and data standards.

In particular, it describes how those developing data about some aspect of health can obtain assistance with, or endorsement of, their data development work.

Engaging with the national health information committees

Which are the key national health information committees?

The National E-Health and Information Principal Committee (NEHIPC) reports to the Australian Health Ministers' Advisory Council (AHMAC) and through it, to the AHMC.

NEHIPC has overall responsibility for advising AHMAC on e-health and information strategies, and for facilitating collaboration between the Commonwealth, States and Territories to implement these strategies.

It provides advice to governments on needs and priorities for health information. For example, recent effort has focused on e-health, on developing measures to monitor the performance of Australia's health system, and on information about the health of Aboriginal and Torres Strait Islander people.

NEHIPC has delegated the functions relating to national data development, including negotiating and agreeing on health data standards, to its sub-committee, the National Health Information Standards and Statistics Committee (NHISSC).

NHISSC is responsible for providing strategic advice on issues relating to health information standards; endorsing national information standards for the health sector and endorsing specifications for statistical collections of national health information.

Various other committees relate to the NEHIPC and the NHISSC. These are shown in Figure 1.

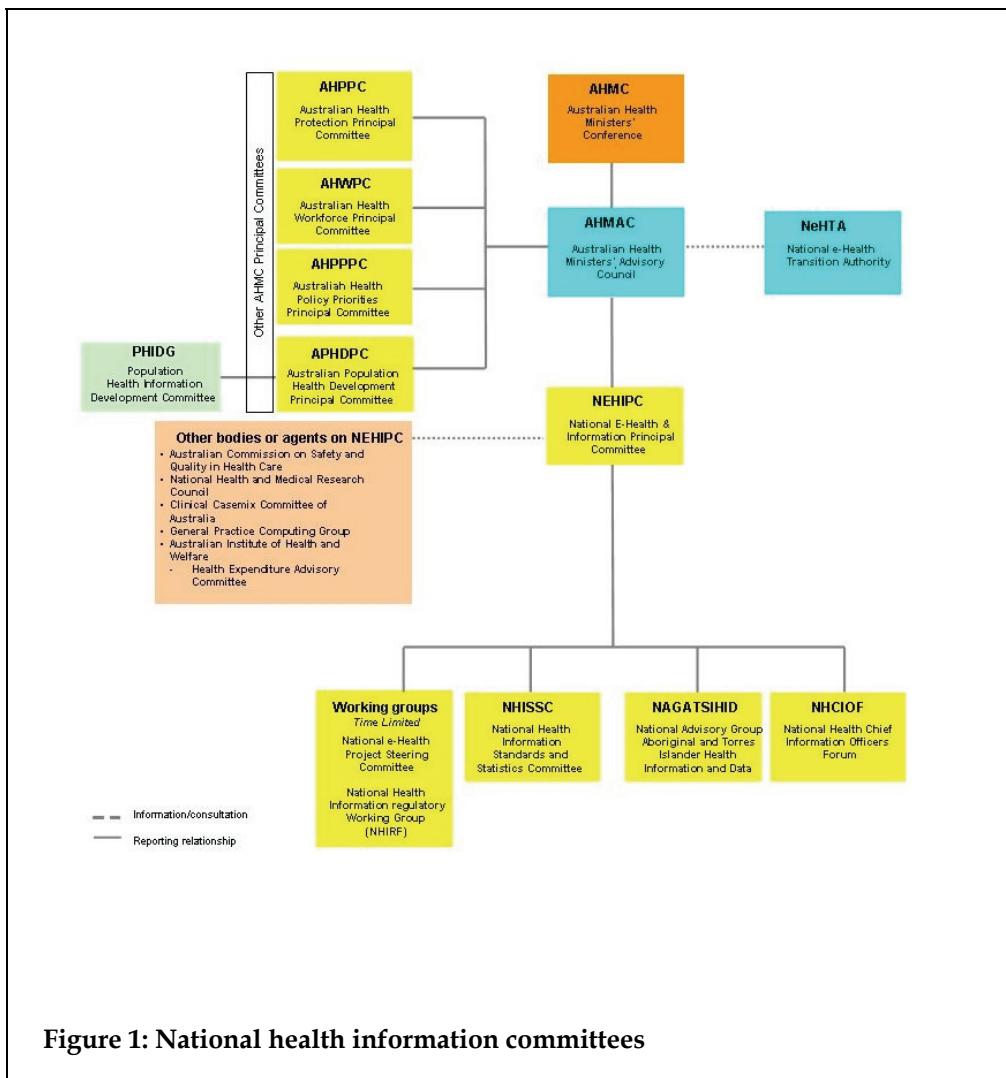


Figure 1: National health information committees

What does the NHSSC do?

NHSSC carries out two key roles in the national information governance arrangements in relation to data development. It is the authorising body for:

- data standards that underpin national reporting, including standard definitions of data items (such as a diagnosis or procedure) or standard specifications of data sets (such as a data set describing the operations of public hospitals); and
- protocols for statistical and analytical methods that affect the creation or use of health information (such as data confidentialisation and data linkage).
- Its major responsibilities include sponsoring data development activity and endorsing the outputs of such activity as national information standards.

What is ‘data development’?

Data development is the process of building a data set for a specific purpose. For example, one might wish to build a data set that supports research into cancer diagnoses, treatment

and outcomes, or one that supports statistical reporting about the operations of hospital emergency departments.

Data development demands a clear understanding of why the data are needed – for example, to underpin the design and evaluation of health policy, or to assess the performance of health services, or to support research into patterns of disease.

It also requires an assessment of the practicalities of collecting the data. Health services are delivered by diverse providers operating in a variety of settings under different public and private governance, management and financial arrangements. Building almost any data set will demand the assembly of data from multiple sources. Thus –if valid national data are to be compiled– there must be an understanding of the diverse information systems from which the data are drawn, and there must be an effort to apply or develop common standards for concepts, classifications, terminologies, data values and so on.

Successful data development requires a variety of expertise – typically, clinical expertise (relating to diseases and treatments), health service expertise (relating to the settings and delivery of services), statistical expertise (relating to data collection, quality assessment and analysis) and informatics expertise (relating to concept formation, definitions and metadata).

For more information about the data development process, see the AIHW publication, *A guide to data development*, available at:

[<http://www.aihw.gov.au/publications/index.cfm/title/10422>](http://www.aihw.gov.au/publications/index.cfm/title/10422)

Why should I engage with the NHISSC?

Over several decades, the national health information committees in various forms have overseen the development of standards for compiling and reporting health information.

This work – which has been undertaken collaboratively by health information experts, clinicians and others from the Australian, state and territory governments and from the private sector – has generated considerable expertise. It has also created some major infrastructure, including:

- the National Health Data Dictionary, which provides standard definitions of health data items;
- the suite of National Minimum Data Sets, which are the basis for the supply of consistent jurisdictional data that are assembled into national reports on the operation of Australia's health system; and
- METeOR, an on-line repository of health and other metadata (data about data, that assist their assembly and interpretation).

For more information see:

[<http://meteor.aihw.gov.au/content/index.phtml/itemId/181162>](http://meteor.aihw.gov.au/content/index.phtml/itemId/181162)

Those developing new data sets may find it valuable to engage with the NHISSC in order to:

- draw on their expertise in conducting data development projects;
- ensure that the concepts, classifications, terminologies, etc being developed for the new data set are consistent with those already in place for other data sets; or
- seek the committee's endorsement of the new data set as a national standard.

The NHISSC has established processes for data development projects including:

- registering a data development project on a committee's work program;
- auspicing the working group that is undertaking the data development;
- checking consistency of the project's recommendations with national standards;
- assessing the business case for implementing a data collection; and
- transmitting a recommendation to the parent (or principal) committee.

Attachment 1 provides further information on the health metadata development process. It is not necessary, however, for those planning to develop a health data set to understand or wrestle with all the details of these processes. It is more valuable to make contact with the information committees and to open a conversation about what work is planned and how to begin engagement with the committees.

How do I contact the NHISSC?

The first point of contact for someone planning to undertake health data development is the NHISSC Secretariat at the Australian Institute of Health and Welfare (AIHW).

The NHISSC Secretariat will ascertain what data development activity you are planning, what information need it will satisfy, who has commissioned or is sponsoring the activity, who is involved in the data development, how far your work has progressed, and what eventual use will be made of your work.

Typically, the Secretariat will suggest that before you make a formal approach to the committee, you arrange a conversation with someone who has experience in developing national collections for the field in which you are working or an allied field. It might be helpful, for example, to talk with a member of NHISSC who has interest in and experience of the field in which you are working, or with subject matter and health informatics (metadata) staff of the AIHW. The AIHW maintains the data dictionary and is the custodian of national minimum data sets.

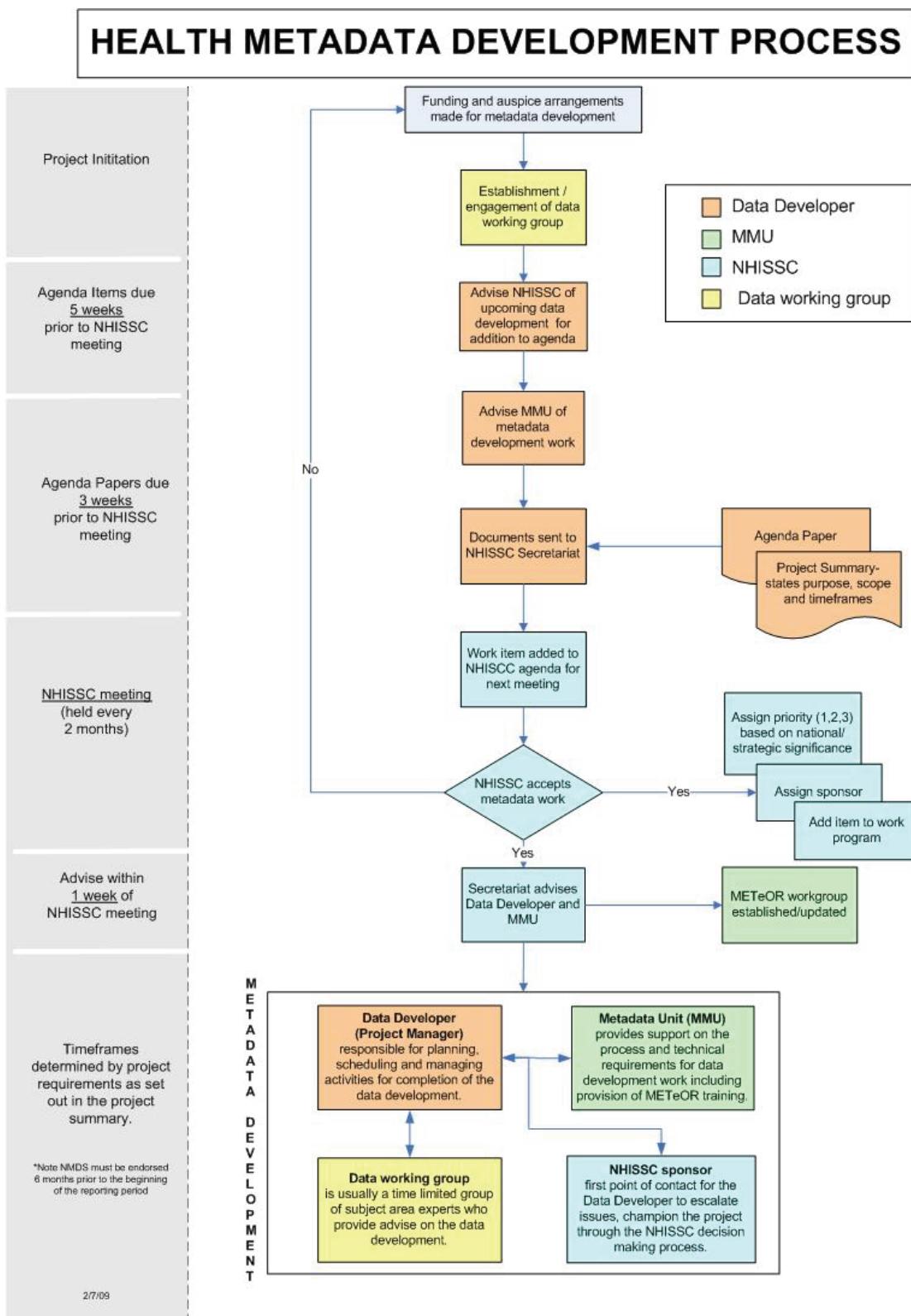
The next step is to prepare a paper for the committee setting out the context and content of the planned data development. The paper should be sponsored by a member of NHISSC and submitted through the NHISSC Secretariat.

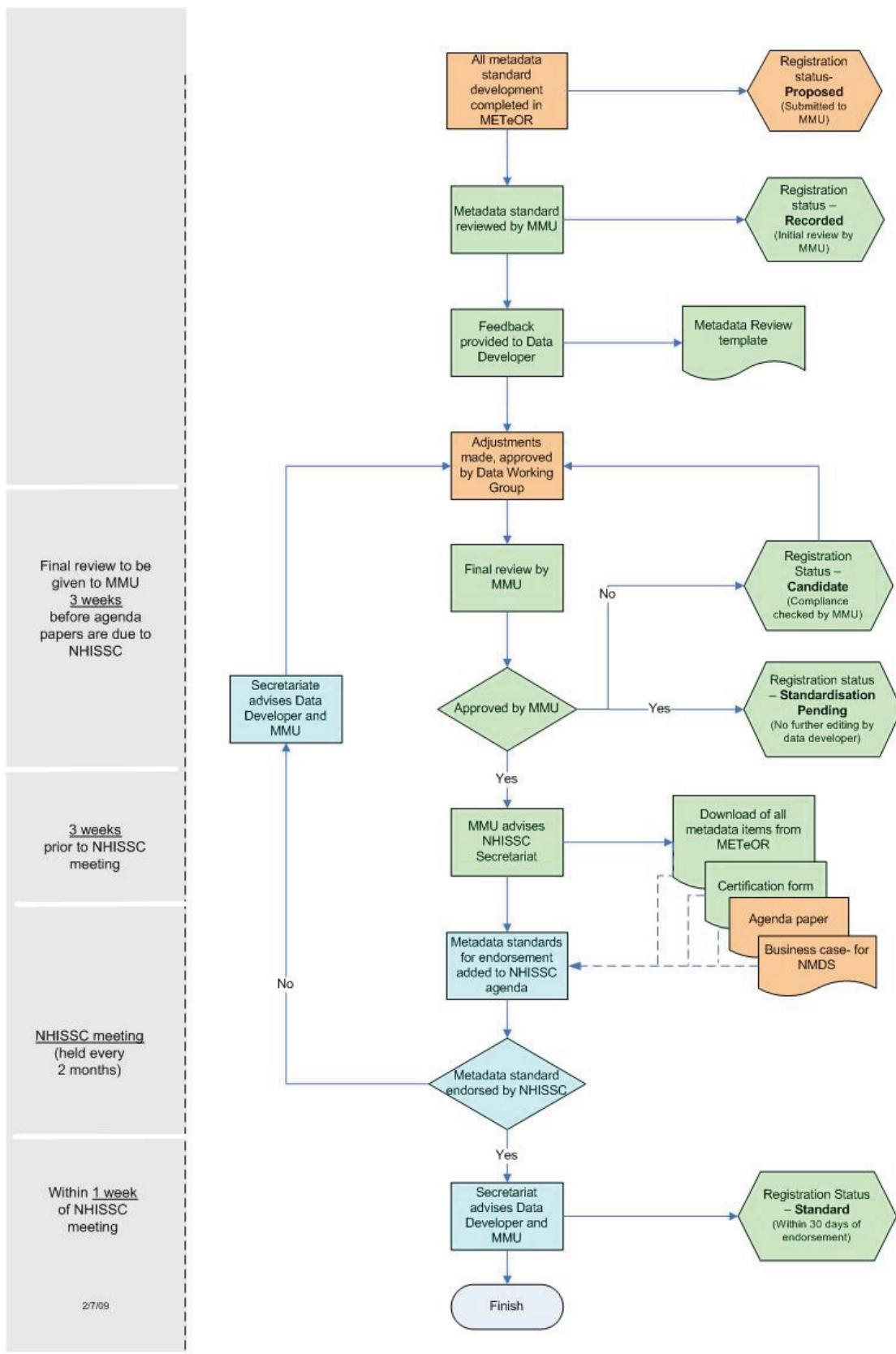
Contact the NHISSC Secretariat

Phone: 02 6244 1033

Email: NHISSCsec@aihw.gov.au

Attachment 1





The Health Metadata Development Process applies to all metadata including Data Elements, Data Set Specifications and National Minimum Data Sets in the Health Sector. The data development process is described under the NHISSC governance process including timelines, other committees and necessary forms.

Funding and auspice arrangements made for metadata development

If applicable, external funding and auspice arrangements should be made as soon as possible. If any part of the project is dependent on the AHMAC-cost-shared budget, the budget bid must be submitted by end of the calendar year.

Establishment/engagement of data working group

Interested parties are brought together as a working group (usually a time limited group) to develop, discuss and provide subject matter endorsement on the data development. This group may be coordinated by the lead data developer.

Advise NHISSC of upcoming data development for addition to agenda

NHISSC must consider a data development project before it is accepted on the Work Program. The data developer must advise the NHISSC secretariat 5 weeks before the meeting date about an upcoming item for the agenda.

Advise MMU of metadata development work

The lead data developer should advise the AIHW's MMU (METeOR and Metadata Unit) of the proposed item of data development on the next NHISSC agenda. This will assist MMU in allocating resources against a work program.

Documents sent to NHISSC Secretariat

Agenda paper - 3 weeks before the NHISSC meeting an agenda paper (using NHISSC standard template) is to be forwarded by the data developer to the NHISSC secretariat for distribution to the NHISSC. The agenda paper should provide the background to the project and give reasons for the data development.

Project summary - 3 weeks before the NHISSC meeting a project summary (using the standard template) is to be forwarded by the data developer to the NHISSC secretariat for distribution to the NHISSC. This should be developed in consultation with the data working group with assistance from the AIHW's MMU. The project summary must include project scope, timeframes and the composition of the working group.

In the agenda paper clearly identify any funding that has already been allocated, external, AHMAC etc. where possible identify a NHISSC member that may be suitable to champion the project.

Note, for the collection of new data items in an NMDS to take effect on 1 July for the reporting year, the dataset must be endorsed by December of the preceding year (for example, December 2009 for the reporting year 2010/2011). This allows each of the agencies agreeing to collect and submit the data to organise, test and implement the changes to their business processes and systems.

Work item added to the NHISSC agenda for next meeting

The NHISSC secretariat adds the data development project to the agenda of the next NHISSC meeting. NHISSC meetings are held every 2 months.

NHISSC accepts metadata work

The data development project is discussed at the NHISSC meeting. If the metadata work/project is accepted by NHISSC it will be:

- added to the Work Program,
- assigned a priority code based on a number of factors, including its national or strategic significance and accordance to strategic needs and emerging priorities
- assigned a Project Sponsor, a representative of the NHISSC who is responsible for guiding the project through the Committee's decision-making process. The sponsor champions the project through the committee decision-making process including recommending the finalised project for NHISSC endorsement. The Project Manager, who undertakes the work, must keep the Sponsor informed of the progress of the data development. The Project Manager must also prepare progress reports, as requested by the Sponsor, for reporting back to the Committee.

Secretariat advises Data Developer and MMU

Within one week of the NHISSC meeting the secretariat advises the data developer and MMU that the metadata work was accepted by NHISSC.

METeOR workgroup established/updated - MMU will organise for a METeOR workgroup to be set-up or for an existing workgroup to be updated. MMU can also provide METeOR training for data developers.

Metadata Development

This is the period in which all of the actual data development work occurs. Timeframes for this work is determined by the project requirements set out in the Project Summary including number of data elements and date of implementation. An NMDS must be finalised and endorsed six months before the standard is to be applied. Establishing which NHISSC

meeting endorsement will be sought out will help establish timelines for the data development.

The Data Developer (Project Manager) works with the AIHW's METeOR and Metadata Unit (MMU) and the data working group to develop the metadata items that will be stored in the national metadata registry system, METeOR. Data collected for national reporting purposes, must be defined in a standardised way. The standard adopted for health data is the International Standards Organisation's metadata registry standard (ISO/CEN 11179:2003).

METeOR and Metadata Unit (MMU) is involved throughout the data development process and provides a valuable resource for data developers. MMU provides support to the data developer regarding the process of data development and the technical requirements for data development. MMU is also able to provide METeOR and Metadata development training to the data development group.

Data working group comprises members with expertise in the subject area of the data standards project. It may be a time limited group set up specifically to do a piece of data development or it may be an existing group that is used to assist in the data development process. The working group provides advice to the data developer on the subject specific matters related to the data development. In some cases the Data working group will want to endorse metadata before it is submitted for NHISSC endorsement.

NHISSC sponsor is a member of the NHISSC that is responsible for supporting the data development project. The sponsor will monitor the progress of the work, ensure that there is appropriate jurisdictional consultation and report regularly on the progress of the project to NHISSC. The sponsor is the first point of contact for the data developer to escalate issues and they champion the project through the data development endorsement process with NHISSC.

Metadata standard development completed in METeOR

All metadata standard development is completed, including all of the metadata is documented in METeOR and discussions have been held between the data developer and the working group to reach agreed data standards.

Registration status (in METeOR) is changed to 'Proposed' by the data developer, the metadata is then ready to be reviewed by the Metadata unit.

Metadata standards are reviewed by MMU

MMU undertake a comprehensive review of all new and revised metadata standards.

Registration status (in METeOR) is changed to 'Recorded' by the MMU, signifying that an initial review has been undertaken by MMU.

Where a change affects any National Minimum Data Sets (mandatory national collections), the MISU advises the Data Stewards of the specifications, of pending changes and notifies the Secretariat of its affect on other standards in the Registry. The Secretariat notifies the Project Officer of potential affects on the change(s) on the Registry.

Feedback provided to Data Developer

The first round of feedback is provided to the data developer on the standard Metadata review template.

Adjustments made, approved by Data working group

The data developer receives the feedback from MMU and incorporate comments and makes changes where applicable. Any feedback from MMU that the data developer does not agree with can be documented on the Metadata review template and discussed further with MMU. Once adjustments are made to the metadata there may or may not be the requirement of the working group to review the changes.

Final review by MMU

A last check of the metadata is undertaken by MMU. This is to be provided to MMU 3 weeks before agenda papers are due to the NHISSC secretariat.

Approved by MMU

If the final review finds no other issues with the metadata it will be approved

Registration status (in METeOR) is changed to 'Standardisation Pending' by MMU. No further editing can be done by the data developer. The metadata is ready to be submitted to NHISSC for endorsement.

If the final review does find further problems with the metadata, MMU will provide further feedback to the data developer

Registration status (in METeOR) is changed to 'Candidate' by MMU. Compliance has been checked by MMU and final feedback provided.

Once changes are made a final review will be done by MMU, metadata will be approved and registration status changed to standardisation pending (see above).

MMU advises NHISSC Secretariat

Once the metadata is approved, MMU will advise the NHISSC secretariat. This will be done 3 weeks prior to the NHISSC meeting.

The following documents must be prepared by the MMU:

Download of the relevant metadata items from METeOR - Where a data item is to be registered in the National Health Metadata Registry (METeOR) all the accompanying affected metadata items must be included in the download.

Certification form - The AIHW must assure the NHISSC that the metadata items that are to be registered in the National Health Data Dictionary (NHDD) conform to the metadata registry standard. The certification form provides this assurance to NHISSC. A certification

form will be completed by MMU and accompany items being considered by the NHISSC for inclusion as national standards in the NHDD.

The following documents must be prepared by the Data Developer:

Agenda Paper – Using the standard NHISSC template an agenda paper will include the background of the data development, any development issues and details of what metadata is being requested for standardisation.

Business Case – This is only required when an NMDS is being put to the NHISSC. The business case must outline the costs of implementation and of ongoing collection. It must also contain a statement from each of the agencies agreeing to collect and submit the data, that they will supply the data in a form that complies with national standards for the collection as stated in the NMDS.

Metadata standards for endorsement added to NHISSC agenda

The above documents are sent to the NHISSC secretariat and the metadata for endorsement is added to the NHISSC agenda.

Metadata standard endorsed by NHISSC

The Sponsor presents the agenda paper and metadata for endorsement to the NHISSC.

Secretariat advises Data Developer and MMU

MMU (the Registry administrator) is advised to update the Register.

Registration status (in METeOR) is changed to 'Standard by MMU, to new items with a Date of Effect (eg 1 March 2010) and assigns the status SUPERCEDED to the previous standards. Any National Minimum Data Sets (mandatory national collections) that are affected by the changes are also SUPERCEDED and each is replaced with new STANDARD. These new NMDS standards come into affect at the beginning of the next financial year (eg. 1 July 2010)

On completion of the Project, the NHISSC Secretariat will send an AHMAC Budget Acquittal Form to the contact officer for the acquittal of funds – acquittals are required in December and June of each financial year.